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NEUROPSYCHIATRIC DISORDERS AND PARENTAL STRESS DURING THE COVID-19 PANDEMIC: AN ITALIAN RETROSPECTIVE LONGITUDINAL STUDY

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Grazia Maria Giovanna Pastorino[✉] ,
Francesca Operto , Valeria De Simone,
Valentina Vivencio, Chiara Scuoppo,
Chiara Padovano, Giangennaro Coppola 

Child Neuropsychiatry Unit, Department of Medicine, Surgery
and Dentistry, University of Salerno, Salerno, Italy

✉ graziapastorino@gmail.com

ABSTRACT — AIM: The objective of our study is to evaluate the impact that the COVID-19 emergency and the related measures adopted have had on the family management of minors with neuropsychiatric disorders. Another objective of this study is to carry out a first longitudinal evaluation of this impact on parental stress, comparing the data collected before the pandemic with those collected during the lockdown.

METHODS: This is an observational study that involved 271 families of patients already treated at the Child Neuropsychiatry Unit of the Salerno University Hospital between 2 and 23 years (112 with Autism Spectrum Disorder, 86 with epilepsy and 73 with other disorders of neurodevelopment). All participants were given an ad hoc telephone interview and a standardized questionnaire (PSI - Parenting Stress Index-Short Form). The telephone interview showed that a significant percentage of parents reported an increase in their child's daily management difficulties during the lock-down and emotional / behavioral problems, in particular the externalizing disorder. Comparison of the mean scores of the PSI-SF questionnaires completed before and during the lockdown showed a statistically significant increase in scores in the Total Stress scale and in the Parental Distress subscales.

RESULTS & CONCLUSION: The results of our study suggest that the confinement measures and changes in daily routine imposed by quarantine negatively affected the behavioral and emotional dimensions of both children and parents causing a significant increase in parental stress, which is mainly related to feelings of inadequacy in relation to their role in such a delicate situation, and concern for the future.

KEYWORDS — Covid-19; children; autism spectrum disorder; epilepsy; neurodevelopmental disorder.

INTRODUCTION

On January 7, 2020, the Chinese Center for Disease Control and Prevention, analyzing samples taken

from the lower respiratory tract of pneumonia patients of unknown etiology, residing in the city of Wuhan, identified a new coronavirus called SARS-Cov-2. The infection caused by this virus has been called, by WHO, COVID-19 (Park, 2020). The rapid world-wide spread of the virus prompted the World Health Organization to declare the sixth public health emergency of COVID-19 of international concern (Public Health Emergency of International Concern — PHEIC), as established by the International Health Regulations (IHR, 2005, cited in Lai et al., 2020) and declare the international focus of the SARS-Cov-2 coronavirus infection a pandemic, which has caused more than 118,000 confirmed cases in 114 countries and 4,291 deaths (opening provisions of the WHO Director-General at COVID-19 media briefing: 11 March 2020). Until a vaccine and a cure are widely available, other mitigation measures are being taken to help slow the spread of the virus (Qualls et al., 2017).

Italy in February 2020 became the epicenter of the COVID-19 disease in Europe, for which the Italian government implemented more restrictive measures to avoid a rapid spread of the infection, starting the lockdown on March 9, 2020. Some of the measures adopted by the Government were: obligation to stay in one's own homes, movement possible only in situations of need and with self-certification; mandatory use of the mask outside the home; distance learning start (DAD); closure of all recreational and sports activities (cinemas, theaters, museums, gyms, etc.). These restrictive measures have weighed economically and psychologically on the population (Bloschynskyi et al., 2021), due to the fear of contagion and the limitation of personal freedom (Tamer Bakar & Akyürek, 2020) and the drastic reduction of interpersonal relationships (Luca et al., 2020a; Grigoras & Ciubara 2021). These profound changes have led to an understanding of how children and adolescents with neuropsychiatric disorders and their families have lived through this period (Luca et al. 2020b, Baroiu et al., 2021).

The purpose of our study was to evaluate the impact that the COVID-19 emergency and the related measures adopted (closure of schools, closure of rehabilitation centers, traffic ban, etc.) have had on the

family management of children with neuropsychiatric disorders. Another goal of our study is also to carry out a first longitudinal evaluation of this impact on parental stress, comparing the data collected before the pandemic with the data collected during the lockdown.

METHODS

Participants

The study was conducted on 271 families of patients already under treatment at the Child Neuropsychiatry Unit of the University Hospital of Salerno, aged between 2 and 23 years, of which 41.33% diagnosed with Autism (group A), 31.73% diagnosed with Epilepsy (group B), and the remaining 26.94% had a different diagnostic picture (specific learning disabilities, intellectual disabilities, attention deficit hyperactivity disorder ADHD) grouped into a only category of other neurodevelopmental disorders. The number of families in the study initially was 277, but 6 of these chose not to participate. There were no exclusion criteria except for poor parental compliance.

Assessment

All participants were given an ad-hoc phone interview and a standardized questionnaire (PSI - Parenting Stress Index-Short Form) (Reitman, Currier & Stickle, 2002) to assess stress levels within the parent-child relationship.

Telephone interview – the telephone interview is based on 16 total questions created ad hoc to collect general demographic information (e.g. age of parents and their level of education), but above all to investigate how changes in life habits related to lockdown have affected psycho-well-being -physical physique of their children (for example, type of diet, sleep rhythms, increase in problem behaviors, etc.), given the problems related to the pre-existing clinical picture, and the concerns related to the spread of COVID-19 (eg fear of contagion).

The interview includes open and closed questions, and others whose answer is based on the choice of a value on a scale from 1 to 10, where 1 corresponds to the non-occurrence of the situation under investigation and 10 to a high frequency or intensity with which this situation occurs.

Parenting Stress Index-Short Form (PSI) — the Parenting Stress Index-Short Form (PSI-SF) is a self-report questionnaire filled in by parents of children and adolescents in order to investigate their level of stress. The questionnaire are divided into three subscales: the Parental Distress (PD) subscale defines the level of stress that the parent is experiencing in his specific role due to personal factors; the Parent-Child

Difficult Interaction (P-CDI) sub-scale concerns the relationship with the child perceived by the parent as difficult; The Difficult Child (DC) sub-scale analyzes the characteristics of the child's behavior and the parent's perception of having a difficult child, focusing on the child's temperament and behaviors. In addition to the scores in these three areas, a Total Stress score is obtained from the sum of the three areas.

RESULTS

Telephone interview — from the information collected through the telephone interview it emerged that only 21.03% of parents did not find any increase in the difficulties of daily management of their child during the lockdown; On the other hand, 26.94% recorded an increase, albeit modest, 25.09% considered this increase to be quite significant, 26.94% recorded a significant increase in the difficulties of managing children. The 42.47% of parents of patients belonging to group C (other neurodevelopmental disorders) experienced a sharp increase in difficulties in the quarantine period, followed by 23.21% of parents of patients in group A (Autism Spectrum Disorder) and by 18.60% of the parents in group B (Epilepsy). Among the factors that have had the greatest impact on changes in child management, we find the obligation to stay at home (21.98%), the closure of school and distance learning (16.10%) and the change of daily routine (14.86%). In 10.22% of cases, the suspension of home and center rehabilitation therapies had a negative impact. Only 10.33% benefited from telematic rehabilitation therapies, while the remaining 89.67% no longer continued with any type of rehabilitation. In 47.49% of cases the parents reported a worsening of clinical symptoms, which in 12.18% was severe (of these, 31.04% were parents of children with autism, 46.2% with other disorders of the neurodevelopment and 22.7% with epilepsy).

The 47.61% of parents observed an increase in externalizing problems in their children: 19.19% in mild form, 16.6% in moderate form and 11.81% in severe form. The increase in internalization problems in children was noted by 20.3% of parents; in 8.12% the increase was slight, in 8.49% moderate and in 3.69% a serious deterioration. The 55.35% of parents were very worried about the situation created by the spread of the virus, in particular the fear of contagion, confirmed by 70.11% of the interviewees, followed by the fear that an aggravation of the child's pathology could occur (43.17%) and that the right assistance is not guaranteed in case of need (28.41%), 25.83% of the interviewees said they were also worried about the difficulties in the daily management of the child and 18.45% for the increase in problem behaviors.

Parenting Stress Index-Short Form (PSI) — By comparing the average scores that emerged from the PSI-SF questionnaires completed before the lockdown (Time 0) and during the lockdown (Time 1) it was possible to highlight some significant differences. In particular, during the quarantine, there was a statistically significant increase in scores on the Total Stress Scale (TS) and in the Parental Distress (PD) subscale.

There is a statistically significant positive correlation between the parental distress (PD) subscale and the age of the father ($r = 0.269$; $p = 0.002$) and mother ($r = 0.193$; $p = 0.030$). Furthermore, the Parent-Difficult Child Interaction (P-CDI) subscale was significantly correlated with the age of the child: higher ages corresponded to higher dysfunctional interaction scores ($r = 0.226$; $p = 0.011$). On the other hand, an analysis of mean PSI-SF scores based on maternal education level showed statistically significant differences, particularly in the Total Stress (TS) ($p = 0.043$) and Parent-Child Difficult Interaction (P-CDI) ($p = 0.018$). Post-hoc analysis showed that secondary licensed mothers scored significantly higher than high school licensed mothers on the Parent-Child Difficult Interaction (P-CDI) scale ($p = 0.043$). Mothers with a middle school diploma score significantly higher than mothers with college education on the Difficult Parent-Child Interaction (P-CDI) ($p = 0.005$) and Total Stress (TS) ($p = 0.007$) scales.

DISCUSSION

In agreement with previous studies, the results of this survey provided further evidence that the confinement measures and changes in daily routine imposed by quarantine negatively affected the behavioral and emotional dimensions of both children and parents (Saurabh & Ranjan, 2020), causing a significant increase in parental stress (Cusinato et al., 2020; Marchetti et al., 2020), mainly linked to feelings of inadequacy with respect to one's role in such a delicate situation and concern for the future (Coyne et al., 2020). Consistent with previous literature, the results of the present study also suggest that children and adolescents with neuropsychiatric disorders have a greater difficulty in adapting to large changes occurring in the lockdown period than typically developing peers, and this further stress parenting (Cusinato et al., 2020; Colizzi et al., 2020).

The suspension of teaching activities in the presence and the interruption of rehabilitation programs weighed on the parents, who lost the support of school services, therapists and ASL, with significant consequences, especially for the families of patients with Autism Spectrum Disorder (Drogomyretska et al., 2020; Colizzi et al., 2020). Many rehabilitation centers

have had great difficulty in adopting the telerehabilitation services recommended by the Istituto Superiore di Sanità (ISS, n.d.) and the Italian Society of Child and Adolescent Neuropsychiatry (SINPIA). In fact, out of a sample of 271 children, only 28 continued the rehabilitation therapy in telematic mode. Furthermore, the limitation of medical visits to emergency cases weighed on parents' concerns about not receiving adequate assistance in case of need.

In this work it was possible to compare the data collected through the PSI (Parenting Stress Index)-Short Form to measure the level of parental stress with the results of the same questionnaire administered in the pre-Covid phase, verifying if there were variations in the level of stress that is often present in the parents of children with disabilities regardless of emergencies such as lockdowns.

This comparison revealed an increase in scores in all scales of the questionnaire, with statistical significance in the Total Stress (TS) and in the Parental Distress (PD) subscales. These results suggest that the greater level of parental stress is mainly related to the parent's difficulty in perceiving their own adequacy to the parental role and only marginally to the characteristics of the child or the parent-child interaction.

Furthermore, the parents indicated as critical factors the concern for the situation (high in 53.35% of cases and moderate in 33.95%) and the greater difficulties in managing the child (high in 26.94% of cases and moderate in 25.09%).

In 47.49%, worsening of clinical symptoms was reported, which in 12.18% was severe (of these, 31.04% were parents of children with autism, 46.2% with other neurodevelopmental disorders and 22.7% with epilepsy). The 47.61% of parents observed an increase in externalizing problems in their children, such as aggression and irritability: 19.19% in the mild form, 16.6% in the moderate form and 11.81% in the severe form. The increase in internalization problems in children, linked to the lock-down situation, was noted by 20.3% of parents; in 8.12% of cases the increase was mild, in 8.49% it was moderate and in 3.69% it was severe.

Among the socio-demographic variables considered, both the age of the parents for the parental anxiety subscale (PD) — as the age of the parents increases, the perception of parental stress increases — and that of the child in the Parent-Child Interaction Difficult subscale (P-CDI) — higher ages correspond to higher dysfunctional interaction scores — seem to influence the questionnaire results.

The paternal level of education did not give rise to statistically significant variations in the different PSI-SF subscales, unlike the mother's educational qual-

ification: a lower level of education (middle school) was linked to significantly higher levels of stress compared to a higher education level; in particular in the Total Stress (TS) and Disfunctional Parent–Child Interaction (P-CDI) scales.

CONCLUSION

Finally, the study shows that only 1.11% of the respondents declared that they had used, or that of another family member, the online psychological support services available to the population.

The results of this study provide evidence that changes during lockdown adversely affected the behavioral and emotional aspects of children with neuropsychiatric disorders, and parents with significantly increased parental stress. It could be useful to encourage, through adequate information and an awareness campaign, the use of online psychological services to support the psychological well-being of parents in this difficult period.

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